

Parent Time

A Newsletter for MoSPIN Parents

Volume 21, Issue 2

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Greetings!

This is officially my first issue of the Parent Time newsletter. I have thoroughly enjoyed reading the articles from our families and seeing it all come together in a great and informational newsletter.

This issue of Parent Time has a special focus on "music."

We want to thank the three MoSPIN families who agreed to share their perspectives on the importance of music in their child's lives in this issue. I am personally a lover of music (singing and playing). So I always enjoy seeing other kids and their families finding that same joy I have in music.

Our thanks go out to the Adams, Jenson and McKee families for their contributions to this issue!

Jessica Hall

Jessica.Hall@msb.dese.mo.gov



*"Music expresses that which
cannot be put into words and
that which cannot remain silent."
-Victor Hugo*

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From the Adams Family

Hello parents! My name is Michelle Adams and my daughter Cali is almost one and a half years old! Cali is diagnosed with Septo Optic Dysplasia and Optic Nerve Hypoplasia. This means she was born with her optic nerves severely underdeveloped. The optic nerve is what transports images from the eye to the brain. There is no cure for this condition but with the help of therapy and lots of hard work Cali is able to make the most out of the minimal vision she does have.



This month's topic is music and I have to say how excited I am to tell about how music has so positively impacted our lives! I would love to share our personal experience with you all in hopes you gain some ideas that may work for your little one! Music has always been something that I enjoyed and appreciated greatly, and it was clear from an early age Cali felt the same way. Even when Cali was only a few months old it was clear music brought her a sense of calmness and peace. Her favorite was classical. I then learned to use music in overwhelming or difficult situations for her. Calming music made things like loud or unfamiliar places, doctor's appointments, tests, labs, or just a fussy time a lot more bearable. Thank goodness for technology and nursery rhyme apps! Of course, when all else fails, mom's voice is always a favorite as well, no matter how bad you think you sound!



As Cali grows older, music has become a teaching aid for me as well. I continue to find new ways to use music as a learning tool for Cali. Through the use of toys with buttons or things you can push to make sounds, Cali has begun to learn the concept of cause and effect. She now knows that if she does something like push a button, she will get a reaction—music! This is also good for teaching her that SHE is the one causing the effect! This is a very important skill to learn, and she enjoys it so much. Making things into songs is also another great way to help Cali engage more with what I am trying to teach her and makes some things easier to remember. For example, I started singing “head, shoulders, knees and toes” to Cali

and at first I would just touch her with my hands. Then after she became familiar with the song and what I would do, I began to use her hands as we sang the song. Cali will now point to all of her body parts (except her toes, we're still working on that!) by herself! She lights up with a huge smile when I sing this song and it has helped her identify important parts of her body!



I have also used music to help Cali with identifying her placement in our home. I will play some music on my phone and Cali and I will walk in and out of the room, and to different places of the house. This has helped her begin to understand some concept of space and orientation. Sometimes placing the music in a room a little further away and having Cali walk to find it has also been helpful. (I must add I feel it is important for children to also go without music playing to listen and learn the natural sounds of the home as well, such as the refrigerator or a ticking clock.) Music has encouraged Cali to move as well! Cali loves to dance and walk in circles. She even has a handful of favorite songs that bring a smile to her face and make her want to groove! To this day music does something special for Cali. Not only does it help her learn and explore, but it brings her a certain happiness and tranquility that I am truly thankful for. I feel the possibilities with music and our children are endless! I hope that some of our experiences will help you and your little ones. There are also a tremendous amount of tips, tricks, advice and resources online regarding music and how we can implement it into our kiddos' lives! Don't ever be afraid to sing and rock on!



From the Jenson Family

Hello! We are the Jenson family. Cory, Aleta, Preston 17, Alivia 15, Bethany 14, and Nathias 4½. Our oldest, Maren, not too long ago, moved out on her own so we are down to 6 people in the house. Nathias joined our family through adoption as a newborn. He has hydrocephalus, multiple brain malformations, and has a seizure disorder but has been seizure-free for quite some time now. His visual impairments include optic nerve hypoplasia, cortical visual impairment, and nystagmus as his main visual diagnosis. Because of all this, he is severely delayed in his development but he does continue to make strides and he is an absolutely amazing kiddo! Right now we are working on walking and are trying to get a walker to use at home since he is doing so well with one at school. Hopefully before too long he will be getting around the house on his own!



We always say Nathias came to the right house because our family is very musical and Nathias absolutely adores music! All of the kids play at least one instrument and the girls sing as well. I play the piano and organ and sing some. I have been going to school the past few semesters to round out my music education a little bit to better help my kids with their music education. It has also been helpful where Nathias is concerned. It has started to open up my eyes more to what music can do for an individual, especially a person who is visually impaired.

When Nathias was tiny we would take him to all

of the concerts the kids performed in and he absolutely loved it! Now that he is a toddler and has an early bedtime, he sometimes doesn't enjoy it quite so much but he has been exposed to a variety of music in our home because of all the practicing that goes on! Nathias loves musical toys and really enjoys playing the piano. He wants to listen to "his" music all the time in the car and he doesn't appreciate it if we listen to the radio. He likes anything that is geared for children and especially sung by children. He tolerates Christian rock music but any other kind of alternative music he will not listen to for long without hollering about it! There is hardly a moment that goes by where he doesn't have some form of music that he is either listening to or participating in.



One of the ways we have found music to be particularly helpful is by using it as a motivator and a reward for getting him to do things he may otherwise not enjoy doing. For example: even though he is doing quite well with walking now, he has struggled to have the motivation to want to walk. It is physically difficult as well as visually complex and because he has a handful of people to carry him he hasn't seen the need to walk. So we have a few songs that he loves and he can be persuaded to walk if you sing them to him. The "Ants Go Marching" and "Five Little Ducks" work almost every time!

We have recently started using music when we go places where he is stressed out by sounds he doesn't care for. He is very sensitive to certain sounds: blenders, lawnmowers, water running, air conditioners, carts screeching on the pavement at the grocery store, other children's high-pitched screaming, loud speakers, and so on. Crickets,

frogs, and birds chirping keep him awake at night or wake him early and make it hard for him to sleep. I don't know if others experience large amounts of sound sensitivity but we do! So we take along an iPhone wherever we go and play his favorite albums quietly so he can listen to enjoyable sounds while being exposed to the unpleasant sounds. It helps him keep calm in stressful situations. At night we have a special CD he listens to that is designed to help calm him and lower his heart rate so he can sleep. Sometimes we keep the CD playing quietly to help drown out the other disturbing noises so he can sleep better. I love how this has reduced a lot of his early morning waking! I am so glad to have very few 1:30, 3:00 or 4:00 wake times since we got this CD! A nightly dose of melatonin has helped as well but not as much as this music seems to!



Another way we are using music is to encourage him to sing or talk. We sing part of a song that he has heard and then stop at the end of a line and wait for him to say the words. Right now we are using "Twinkle Twinkle Little Star" to get him to say star and the 'ahhh' sound. One of my college courses requires me to practice sight singing by using something called "solfege". In short, this means that I am reading music on a page without the use of the piano and each note corresponds with a syllable. You may recognize it from the movie "Sound of Music" when they sing the song with "do, re, mi, fa, sol, la, ti, do." I use those syllables to do my sight singing and Nathias loves to try and sing "do, re, mi" with me.

He has recently started music therapy and I highly recommend this! He really enjoys this kind of therapy! The therapist is helping us identify

more ways for music to be helpful for him. As you can see, we use it a lot because he loves it so much! It is my opinion that the life of a multiply disabled, visually impaired child is a frightening existence and often overwhelming but at the same time dull because there is so much they miss by not having good vision. Music provides a way for them to more fully engage in life and enjoy it more, while stimulating their little brains to help make up for what they lack in vision. It is amazing to me how much he has come to enjoy it!



From the McKee Family

Hello again MoSPIN families! We are the McKee family, and we are thankful for this opportunity to write for Parent Time. Our son, Carter, is two years old and has CHARGE Syndrome. CHARGE effects our son in many ways, but with regard to vision he has a condition called micropthalmia. For Carter, this means he is legally blind in his left eye which is his smaller eye. He is near-sighted in his right eye and wears glasses for correction. Carter is also bilaterally profoundly deaf and had bilateral cleft lip and palate. Carter has a cochlear implant on his left side and is now testing in the normal range when aided! Since we last wrote, Carter was able to have his cleft palate repaired. The last month has been a very exciting time for our family as we have really seen gains with increased vocalizations and imitations.



I was very excited that the topic of this Parent Time issue is music because Carter absolutely loves music! Carter has always been motivated by music which came as a surprise to us as many say children with cochlear implants are not always receptive to music. It improves his mobility, engagement, and auditory skills. Due to all of this, we have chosen to obtain private music therapy for him. I thought I would outline a few of the skills that he has been able to work on with his music therapist. I do give the disclaimer that much of what we use music therapy for is related to his hearing loss.

- **Mobility:** Carter is very motivated to move by music. When we want Carter to walk or move, we will often sing a little song that describes his movement. For example, "Carter is crawling, crawling, crawling, Carter is crawling across the floor." His music therapist will also play guitar and strum the guitar as she steps to attempt to get Carter to walk in a rhythm. This is very motivating, and she will also stop the music periodically to help him understand the stop command.

- **Auditory Comprehension:** Carter works on many listening tasks. We have songs associated with many tactile objects. The therapist will sing the song and Carter is to pick up the tactile object that goes along with the song. Carter is much more receptive and engaged when we sing a song versus just simply telling him the name of the object. He also is able to get more repetition of the words and increased vocabulary through the song. Another task he does is to listen to the commands associated with different instruments. For example, she will sing "round and round and round....etc." while he rotates a bead drum in a circular motion. She will then stop and start singing "tap, tap, tap" and he must begin to tap on the top of the drum. The beat of the song changes depending on the type of motion and instrument. The pace of the music changes and he must also change the pace to his movement.

- **Speech and language:** Music is used to illicit speech sounds. She will often work on auditory closure and start to sing a common song such as

"Twinkle, Twinkle Little Star." Then she will suddenly pause in the middle for Carter to say the word that would be in that specific part of the refrain. For example, "twinkle, twinkle, little _____" and he is expected to make some sort of vocalization or to sign the word star.

- **Sensory:** The music therapist brings a variety of musical instruments each week. Carter is able to tactilely and visually explore each instrument. She often presents two and allows him to make a choice after tactilely exploring both. She sings about the instrument (the name and the sound the instrument makes) as he explores it. The instruments are made of many different materials (metal, wood, cloth, etc.) and many different textures. She also allows Carter to explore with his hands and also his feet (which he loves to explore with!).



Finally, I wanted to share some of my favorite resources related to music:

- **Baby Signing Time (DVD or Digital Videos):** Carter loves Baby Signing Time. We have found it to be an extremely effective way to teach him sign language because it is all musically based and completely engaging. The instructor also does a pretty good job of describing the sign when she is teaching it.

- **Baby Beats:** This is a FREE program you can request through Advanced Bionics (One of the three companies to make Cochlear Implants). I'm not sure if you must have a child with hearing loss, but you simply go on the website and put in a request. This is designed for parent use and has a CD and parent guide with activity ideas. This is incredibly easy to implement and honestly has tons of auditory comprehension ideas without the hefty cost of music therapy.

- **Free community music programs:** We take advantage of several music programs that are free through various community organizations. Our local library provides “Rhyme Time” which is a time of music and movement twice a month. We also attend a local nature center that has programs for babies that always incorporate music. When we are in the St. Louis area for a medical appointment and there is ever opportunity for us to attend a “Buddy Builders” program at the Delta Gamma Center, we are sure to join in. During music time there, the teacher is sure to incorporate tactile representations during the songs. It is great for our kids to be around other kids enjoying the social aspect of music. I encourage you to explore your community resources for musical opportunities for your child.



One final thing I want to make mention of is that we sing all the time to Carter. We sing about what we are doing, where we are going, and how he is feeling. We feel that the more we talk and sing, the more we immerse him in language. The repetition and rhyme are engaging to him, and he is more aware of what is happening. I encourage you to try this. Remember, they don't care how well you sing. They already love your voice because it is yours! Music is such a powerful tool to motivate. While music therapy can be expensive, there are definitely things that you can do on your own at home. We hope this article was helpful in sharing some of those strategies with you.

The McKee Family: Tom, Amanda, & Carter



Music Braille Code

Many of you may be thinking about introducing Braille to your child. If this is the case, you may want to begin music lessons in Braille. Here is a link to a pdf file that provides everything you need to know about Braille music! Music in Braille is completely different than reading or writing in Braille. So you may want to get a head start!

http://www.brailleauthority.org/music/Music_Braille_Code_2015.pdf



Music Together

The link below is a great tool when looking for music classes close to you. It also provides you with some helpful tips and activities to use with your child.

<https://www.musictogether.com/>



Apps

What better way to learn music than with a phone or tablet?! I always find it helpful when I can access materials right from my phone or ipad. These apps could be beneficial when going on a long car ride, waiting for an oil change, or just needing another activity to keep your little one entertained at home. Some are free and some are not, but they all provide an extensive amount of tips, tools, activities and games to incorporate music into your child's life.



2-Player Xylo

Musical instrument that lets you play a realistic-sounding xylophone with 2 people at once.



Piano Hero

Play the piano on an iOS device with this app.



Easy Xylophone

Play music on this realistic-sounding xylophone app.



Angel Harp

Play with this app like it's a real harp.



Virtuoso

Virtual composer for iOS.



Tappy Tunes

Enables users to play music without learning an instrument.



Juno's Piano

This musical learning app introduces users to playing the piano.



BouncySounds

Touching the screen accelerates the bouncy ball like an elastic band. Let go to get it to maximum speed, and it will randomly trigger sounds while it gradually slows down.



Baby's Musical Hands

An app safe for children to use on their own while they play with musical buttons and sounds.



Music Sparkles

This app brings a world of music to the fingertips, from piano and xylophone to electric guitar.



PianoBall

This app encourages children to explore music and color in a creative way. Once the instrument is chosen, the stars will guide the user to play a tune.

Wonder Baby

Wonder Baby is a great website that provides a lot of helpful resources and tips for kiddos who are visually impaired. The links below direct you to some fun ideas to promote music in day-to-day life.

<http://www.wonderbaby.org/articles/music-teach>

<http://www.wonderbaby.org/articles/babies-music>

<http://www.wonderbaby.org/articles/music-development>



MoSPIN News

**WHEN YOUNG CHILDREN
ARE CONSISTENTLY
ENGAGED BY MUSIC IN
AN AGE-APPROPRIATE,
SOCIALY ACCEPTING
ENVIRONMENT, THEY
BENEFIT AT MANY
LEVELS INCLUDING
SOCIAL-EMOTIONAL,
PHYSICAL, CREATIVE,
QUANTITATIVE AND
EARLY LITERACY. AND
OF COURSE, THEY
DEVELOP A LIFELONG
LOVE OF MUSIC.**

~We Love Kindermusik - Created by Grow and Sing Studios

I wanted to introduce myself to those of you who may not have heard the news. I took over Ginny Williams' position as the lead Parent Advisor for MoSPIN beginning on March 1, 2016. I am so excited to be on this new journey with you! I was previously a TVI (Teacher for the Visually Impaired) in Columbia, Missouri, for 3 years. I was married in August, 2015, and moved north to Green City, Missouri, about 30 minutes west of Kirksville. I am learning what it's like to live in a small country town. My husband is a pig farmer on his family's farm. Not exactly what I imagined my life being like after 9 years of school, but it makes me happy and I love every minute of married life.

I also have a 6-year-old step-son who is in first grade. We are involved in a small country church that fills my heart with joy. I have the opportunity to play the piano as much as I have time for, which blesses me to no end. I look forward to being your lead Parent Advisor and providing you with a wonderful opportunity to learn and grow as a family. Please do not hesitate to call, email, or text me with questions, concerns, or just to visit. Thank you!

Contact Jessica Hall, Lead Parent Advisor for MoSPIN



Jessica Hall (or) MO School for the Blind
1702 E. Laharpe St. 3815 Magnolia Ave.
Kirksville, MO 63501 St. Louis, MO 63110



660-785-2317 (work)



573-289-9441 (cell)

Jessica.Hall@msb.dese.mo.gov

Need Web Assistance?

Many of the articles in this issue of Parent Time refer you to websites. If you do not have access to the Internet, just ask your MoSPIN Parent Advisor to assist you. I am also available to provide information or hard copies of resources. You can contact me at 660-785-2317.

Jessica Hall

Lead Parent Advisor for MoSPIN



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